

## CFC #2 News to Use

Volume I, Issue I

Fall 2008

## **Meet Austin**

By Frannie Jahnke, Parent Liaison

#### Websites of interest:

Child and Family Connections #2: www.co.lake.il.us/health/chs/ family/cfc/cfe.asp

Illinois Early Childhood Intervetnion Clearinghouse: www.eiclearinghouse.org

IL Early Intervention Training: www.illinoiseitraining.org

StarNet Region II: www.thecenterweb.org/ starnet/

#### Inside this issue:

Meet Austin

Local Interagency Council for Early Intervention	2
Child & Family Connections #2 Play Dates	3
Parent Liaison Services	3
Going Green	4
Upcoming Events	4

I sat pondering this thought, "how should I introduce myself to you?" When I realized, that maybe it's not me that I should introduce, but rather, maybe I should introduce the individual who brought me to where I am at today.

Meet Austin.

Austin was born unexpectedly at 26 weeks gestation. Out of my other pregnancies I had thought this one was going to be the best. I felt wonderful! No morning sickness, no fatigue! I was energetic. almost blissful. Then one Sunday morning I noticed that Austin had not moved within the past 24 hours. I called my physician who sent me directly to the hospital. After several ultrasounds and neonatal stress tests. I was transferred from my local hospital to one that has a neonatal intensive care unit. I had lost amniotic fluid and the child within me was displaying many signs of stress including heart rate drops.

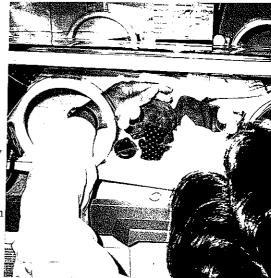
While in this new unfamiliar setting, a specialist was brought into my room to explain the seriousness of my unborn child's distress. It was determined that delivery needed to occur soon because if I went into labor my child would not survive the traditional birth process. So, a cesarean section was performed.

Austin was born August 6, 1987.
Yet, I can still remember its events as if it were yesterday. Tears fill my eyes.

I remember how frightened I was to meet him. I remember being frozen to my hospital bed. No matter how I tried I could not lift my legs off the bed. I knew I should get out of bed, walk down to the NICU and see my son. Yet, I struggled just to get out of bed.

When I finally garnered the emotional strength to walk to the NICU, I sat beside him, held his tiny little hand, and wondered why I was so afraid to see him. Yes, he looked fragile and helpless. But, he was alive! Fragile but alive.

This ritual of being stymied, making the decision



to get out of bed, walking down the hall to the NICU and finally sitting next to him, holding his hand, was something I went through several times a day.

Each time I returned to my room I cried. How could I feel this way? This is my child at the end of the hall!

I think the hospital staff recognized my trauma and allowed me to stay in hospital for a week rather than the customary few days. I am thankful for that extra time. Because, it was this extra time that allowed me to confront my own fears of becoming attached to a life that may not survive.

Continued on page 2

Continued from page 1

Well, he did survive.

When Austin was in kindergarten dragging around an oxygen tank, his siblings took him down to the schoolyard and taught him how to go up and down the slide with it. They wanted him to be able to have fun during recess.

When Austin was about 10, his siblings made him get up on a 2-wheel bicycle. They would not let him come into the house until he learned to successfully ride it dragging his oxygen tank behind him.

I think it was when he was in 4th grade, his g-tube came out during PE class. Austin was rushed to the office:

911 was called. The principal, school nurse, and paramedics were unsure as to what to do. The principal told me that Austin looked at all the adults and calmly said, "Just push it back in and tape it down. My Mom will put a new one in when I get home from school."

Austin advocated for himself with his medical team prior to entering middle school. He told his team that he did not want to enter middle school with his g-tube or oxygen. Austin was able to successfully articulate his reasons.

He was diagnosed with exercised induced hypoxia while attending high school. He refused to allow this condition to keep him from joining the swim

team where he developed himself into a 500 meter swimmer.

He is now in college enjoying apartment living in Chicago.

We have had our ups and our downs. Our ups have given my family the fortitude needed to confront difficult

times and decisions. Austin continues to need follow up medical care and I as a mother am still reminding myself to let go and let him advocate for himself.

I have in my office the picture of the woman who began us on our path to independence - his first Early Intervention therapist. She helped our family see Austin the child - and the things he could do - not the things he could not. She empowered my family

by teaching his siblings and I how we could play with him even when he was having difficulty moving his right arm and leg. She empowered me by stepping aside and allowing me the privilege of bonding with Austin while I incorporated the skills she taught me into my day to day activities with him.

My family has a great deal for which to be thankful. Austin's pediatrician once told me that there were 3 things that he felt led to such positive outcomes for Austin: 1) a loving family; 2) siblings that did not see him as different; and 3) the early intervention services he received.

He is right. But, I would take it a little further. Our family was very fortunate to have positive relationships beginning with our NICU staff, who patiently waited for me each day, our pediatrician who supported us in seeking and receiving the medical care Austin needed, Early Interventionists, Early Childhood staff, our home school district staff, all the way through his high school experiences. We have many people to thank.

Times have not always been easy but they sure have been interesting!

# Lake County Interagency Council for Early Intervention

(LIC) Contact Darla Walker at 847-782-6299 or dwalker@co.lake.il.us to reserve your seats

The Lake County Interagency Council for Early Intervention is comprised of Lake County families and community agencies working together to promote and ensure a comprehensive, family-centered system for children ages birth to 3 with developmental delays.

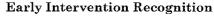
Please come join us as we work together to identify successes and barriers to ensuring this happens. Your input is vital to our growth. Meeting schedule:

9/26/08: 12:00-1:30 p.m.

11/07/08: 12:00-1:30 p.m.

Location: Lake Forest Outpatient & Acute Care Ctr., 1475 E. Belvidere Rd. (Rt. 120), Conference Rooms A&B, Grayslake, IL.

Bring a bag lunch or order one from the café.



Night: Join us on 12/17/08 in Conference Rooms A&B of the Lake Forest Outpatient and Acute Care Ctr., Grayslake, IL, 5:30-7:30 p.m. to celebrate our partnerships within our communities.

You are our cause for celebration!



## Child and Family Connections #2 Parent/Child Play Dates

Sponsored by
Child & Family Connections #2 and
Lake County Interagency Council for Early Intervention

Facilitated by Jon Ashworth, CFC #2 Social-Emotional Specialist

The Child and Family Connections #2 Play Dates are a time for parents and children to interact in a very fun and child-friendly environment. Some CFC Staff will be present at each of the play dates and will look forward to connecting with you and your child.

Pick the Play Date session that best suits your child -

#### REGISTRATION IS REQUIRED:

To register call Jon Ashworth at 847-782-7506 or e-mail him at jashworth@co.lake.il.us

When registering, please indicate your name, your child's name and date of birth, your phone number, your service coordinator's name and which session you be attending

#### This is a free play group.

Refreshments will be provided.

The first 20 children to respond for each play date will be registered.

October's Play Dates will be at

Children's Neighborhood Museum

Round Lake Area Park District

814 Hart Road

Round Lake IL

9:45 a.m. - 10:45 a.m.



#### Session #1

Thursday, October 16 - Little Wigglers, Early Crawlers, and Early Walkers

(Register by Monday, October 6)

#### Session #2

Thursday, October 23 - Walkers and Runners #1

(Register by Monday, October 13)

#### Session #3

Thursday, October 30 - Walkers and Runners #2

(Register by Monday, October 20)

Watch your mailboxes for other dates and locations of our Play Dates.

### **Parent Liaison Services**

Parent Liaison services were incorporated into the Illinois Early Intervention System to support families receiving services through it.

All Parent Liaisons within the State

of Illinois have a child with a disability who have experienced the Early Intervention System. This provides you and your Individualized Family Service Plan (IFSP) team members an unique support. Parent Liaison services include:

Providing you with specific information about your child's diagnosis/ concerns;

> Assisting you, your Service Coordinator and Service Providers in locating and providing information about services and resources in Early Intervention as well as your community;

Connecting you with other families with similar concerns:

Providing you with information about the transition from Early Intervention to other learning opportunities for your child when your child turns 3 years old;

Attending IFSP meetings and/or other meetings that might be appropriate for your family;

Providing parent-to-parent support: one-on-one either in person or over the phone.

Please feel free to contact me at 847-782-6151 or fjahnke@co.lake.il.us.



204

#### **CHILD AND FAMILY CONNECTIONS #2**

2424 Washington Street, Suite 210 Waukegan IL 60085

Phone: 847-782-6151 Fax: 847-360-3176 E-mail: F]ahnke@co.lake.if.us

Empowering Families

# Trying to go Green

In an effort to conserve natural resources, time and money, we are trying to go green at the Child and Family Connections #2 office.

Please help us advance our efforts by signing up to receive this quarterly newsletter via e-mail.

If you are interested in receiving this via e-mail please send your email address to

fjahnke@co.lake.il.us

Thanks for your support.



## **Upcoming Events**

Free Bilingual Playgroup for children with Down Syndrome sponsored by the Down Syndrome Developmental Council

When: 3rd Thursday of every month

Where: Gurnee IL

Hosted by Developmental Therapist, Kris Murray.

RSVP by the morning of the playgroup: Developmental Therapist, Kris Murray, at 847-630-4991 or email Belinda Hildalgo at Belinda.hidalgo@alere.com.

Siblings are welcome.

Spanish and English Interpretation is available.

October 24, 2008: Helping from Heaven Masquerade Gala for more information call 847-624-5394

October 25, 2008: Hearing Aides of Illinois & John Powers Center: Halloween get together for families who have children who are deaf/hard of hearing. For more information call Debbie at 847-543-6822

November 14-16, 2008: Jewish Child and Family Services (JCFS) Glick Family Camp: designed for children diagnosed with Autism/ PDD, Cerebral Palsy, Mental Retardation, Spina Bifida, Motor & Cognitive Delays & Medical Conditions & their families. For more information call Tammy Besser at 773-467-3751

December 6, 2008: Spina Bifida Association of Illinois Holiday Party in Rolling Meadows. For more information call 773-444-0305